

MINUTES OF THE SENATE HEALTH CARE STRATEGIES COMMITTEE

The meeting was called to order by Chairperson Susan Wagle at 1:30 P.M. on February 21, 2006 in Room 231-N of the Capitol.

Committee members absent:

Committee staff present: Ms. Emalene Correll, Kansas Legislative Research Department
Ms. Terri Weber, Kansas Legislative Research Department
Mr. Jim Wilcox, Revisor of Statutes Office
Ms. Margaret Cianciarulo, Committee Secretary

Conferees appearing before the Committee: Mr.. Robert Twillman, Ph.D., LIFE Project Pain Management Task Group, UMKC
Mr. John Carney, Vice President, Aging and End-of-Life Center for Practical Bioethics

Others in attendance: Please see attached Guest List

Presentation on End-of-Life

Chairperson Wagle opened the meeting by announcing there would be a presentation on the above topic and introduced the first of two conferees, Mr. Robert Twillman, Ph.D., LIFE Project Pain Management Task Group, UMKC, who offered a history of the Life Project, who it was funded by, its makeup (ex. 100 partners, 36 community organizations, etc.), listed: Pain Management issues (which is what he would be speaking on), **HB2659** (being amended substantially); the criteria for evaluating state pain policies, both the negatives and positives; how states rated including Kansas; improving pain management education; changing policies and Medicare/Medicaid drug coverage. A copy of his testimony is (Attachment 1) attached hereto and incorporated into the minutes as referenced.

The Chair thanked Dr. Twillman and since the next conferee would be speaking on a different topic, asked if there were questions or comments for Dr. Twillman. Questions came from Senators Schmidt and Barnett ranging from: referring to the first page of his handout, "Unrelieved pain costs our economy over \$100 billion each year" - can you identify what goes into this \$100 billion; interested in your comment regarding dispensing "large doses of opioid" (doesn't believe the person is taking all of the prescribed narcotic because she feels, he/she could not physically handle such large doses); is it not true that the Kansas Medicaid does limit dosages to FDA standards unless they go through a prior authorization process; have you looked at the cost of the side effects and adverse consequences of treating with these drugs; to how do you think the abuse of prescription drugs ranks in terms of our overall drug problem in America?

The Chair then introduced Mr. John Carney, Vice President, Aging and end-of-Life Center for Practical Bioethics, whose testimony referred to hydration and nutrition issues and stated this was his third occasion to testify on these matters to the legislature this session. Copies of his previous testimony are being provided as appendices to his testimony. He then went on to state that the remainder of his remarks will draw primarily from his previous testimony to support a list of conclusions and recommendations he had listed in his current testimony including:

- Ex. of a conclusion: the vast majority of Kansans do not have advance directives in place, nor do they readily discuss end of life matters with family or professional care givers, nor are most healthcare consumers familiar with the dying process, advance disease states, or chronic illness and co-morbid conditions;
- Ex. of a recommendation: consider the Kansas Judicial council recommendation regarding the administration of artificial nutrition and hydration for wards of the court (**HB2307** Committee).

A copy of his testimony today and his previous testimony as indices, are (Attachment 2) attached hereto and incorporated into the minutes as referenced.

CONTINUATION SHEET

MINUTES OF THE Senate Health Care Strategies Committee at 1:30 P.M. on February 21, 2006 in Room 231-N of the Capitol.

Page 2

The Chair then thanked Mr. Carney and asked for questions or comments from the Committee regarding Mr. Carney's testimony. Questions from Senators Wagle, Schmidt, and Barnett regarding: what kinds of groups are on this Judicial Council; is the Catholic Church involved; who determines the membership (a request was made that a pharmacist be added); an electronic registry; a website, how to get a pharmacist; POLST; and where are the Judicial Councils recommendations?

Adjournment

As there was no further discussion or testimony and no further business, , the Chair thanked all and adjourned the meeting. The time was 2:30 p.m.

The next scheduled meeting is on call of the Chair.

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

GUEST LIST

DATE: Tuesday, February 21, 2006

NAME	REPRESENTING
Dorinda Klein	Klein Law Firm
Kathly O'Strawder	Kansas for Life
Tom Bruno	The Life Project
Jean Kralw	KS G-ship Prog.
Deborah Long RO	- Washburn graduate student
Just A. Mueller	
Jennifer Kabler	Washburn Student
Ali Sultani	Senate Intern
Mary Ellen Oiler	Via Christi Health System
Michelle Peterson	Capitol Strategies

Please Pass



Pain Management: Policy Considerations for 2006

Robert Twillman, Ph.D.
LIFE Project Pain Management Task Group



Why it's important

“We all must die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is a more terrible lord of mankind than even death itself.”

Albert Schweitzer



Pain is a Major Public Health Issue

- Chronic pain affects 35-50% of adult Americans (50-70 million people)
- 80% of patients present for health care because of pain
- Over 40% of acute care patients report poor pain control
- 50% of dying patients report moderate to severe pain
- Unrelieved pain costs our economy over \$100 billion each year



Drug Addiction is a Major Public Health Issue

- 2004 National Household Survey on Drug Use and Health:
 - 31.8 million Americans had used a pain reliever non-medically at least once in their lifetimes
 - 7% increase from 2002
- 2002 DAWN data (ED visits):
 - 119,185 for narcotic analgesics (73% increase from 1999)



Drug Addiction is a Major Public Health Issue

- 2003 Treatment Episode Data Set:
 - Non-heroin opioids were primary drug of abuse for 9171 patients (534% increase from 1999)



What Makes Good Public Policy for Pain Management?

Senate Health Care Strategies Committee
Date: February 21, 2006
Attachment 1

Reconciling the Numbers: The Principle of Balance



- Public policy makers need to be mindful of the Principle of Balance:
 - Opioid analgesics need to be available for those with pain who need them
 - Opioid analgesics need to be unavailable for those with substance abuse problems who want to abuse or divert them

Criteria for Evaluating State Pain Policies



- Formulated by Dave Joranson and staff of Pain and Policy Studies Group, University of Wisconsin
- Surveys all state pain statutes, regulations, and guidelines
- 8 “positive” criteria, 9 “negative” criteria

Criteria for Evaluating State Pain Policies: Positive Criteria



- Controlled substances recognized as necessary for public health
- Pain management recognized as part of general medical practice
- Medical use of opioids recognized as legitimate professional practice
- Pain management is encouraged

Criteria for Evaluating State Pain Policies: Positive Criteria



- Practitioners’ concerns about regulatory scrutiny are addressed
- Prescription amount alone insufficient to determine legitimacy of prescribing
- Dependence, tolerance ≠ addiction
- Other provisions that may enhance pain management

Criteria for Evaluating State Pain Policies: Negative Criteria

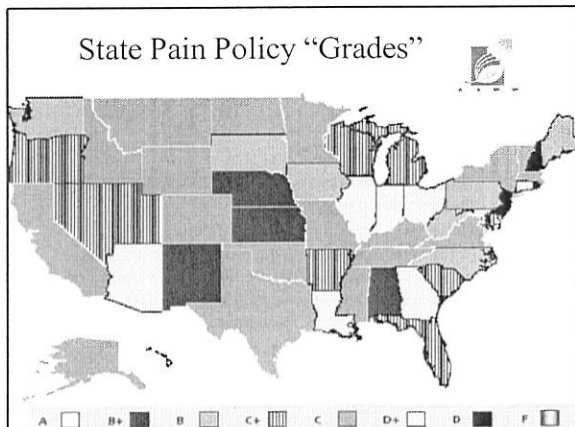


- Opioids are implied to be last resort
- Medical use of opioids implied to be outside legitimate practice
- Belief that opioids hasten death is perpetuated
- Dependence, tolerance = addiction
- Medical decisions are restricted

Criteria for Evaluating State Pain Policies: Negative Criteria



- Length of prescription validity unduly restricted
- Practitioners subject to other prescription requirements
- Other provisions that may impede pain management
- Provisions that are ambiguous



“Positive” Kansas Policies

- Kansas pain policies meet all of the positive criteria except the first
- All of the remaining criteria are met only in pain management guidelines from our licensing boards
- Adding additional statements elsewhere in our policies could be beneficial

“Negative” Kansas Policies

- Prevention of Assisted Suicide Act: Perpetuates the belief that opioids hasten death (Principle of Double Effect)
- Principle of Double Effect is increasingly falling into disfavor--it has not been demonstrated to help with a significant problem in practice

Statutes Prohibiting Assisted Suicide

- Kansas passed anti-assisted suicide legislation in 1992 and 1997
- 1992 legislation made it a criminal offense to assist in a suicide
- 1997 legislation made it a civil offense, and provided for possibility of injunctive relief
- Contain “Principle of Double Effect” language

Principle of Double Effect

- Origins in Catholic moral theology (Thomas Aquinas)
- An act is morally permissible if:
 - The act itself is morally good or at least indifferent
 - Only the good effect is intended
 - The good effect is not achieved by way of the bad effect
 - The good result is proportionate to the bad result

Principle of Double Effect

- In most discussions of assisted suicide, this is invoked to alleviate provider fears
- Attempts to manage pain generally meet these requirements
- But, does this really provide any safe haven? How often does the “bad effect” occur in pain management?

Respiratory Depression and Opioids



- The fear underlying the development of the PDE is that giving opioids will depress respiration and kill the patient
- In opioid-naïve patients, this may not be an unreasonable fear
- In opioid-tolerant patients, respiratory depression can be incredibly difficult to produce via use of opioids

“Negative” Kansas Policies



- Medical Practice Act
 - “Unprofessional conduct” is grounds for sanction from the State Board of Healing Arts
 - One criterion for unprofessional conduct is “Prescribing, dispensing, administering, distributing a prescription drug or substance, including a controlled substance, *in an excessive, improper or inappropriate manner or quantity* or not in the course of the licensee’s professional practice

“Negative” Kansas Policies



- Medical Practice Act
 - This is an ambiguous provision within this act
 - It is not clear how “excessive”...quantity” is to be defined
 - Implication is that this can be determined by counting pills prescribed
 - But many patients with legitimate pain management concerns need large numbers of pills

Means of Improving Pain Management



- Development of practice guidelines
- Monitoring and continuous quality improvement
- Education of providers and patients
- Changes to policies and standards

Improving Pain Management Education



- We are making progress in basic medical/nursing school curricula
 - Highly dependent on having professors with an interest and enough influence to get this into the curriculum
 - Progress is slow, and amount of content is minimal, compared to prevalence of pain
- Need to continue working with faculty/administrators to improve content

Improving Pain Management Education



- Continuing Education is very important
 - Plenty of resources are available
 - Motivation is somewhat low because many healthcare providers think they are doing a good job
 - Some states have mandated continuing education in pain management/palliative care through legislation

Improving Pain Management Education



- We do not favor mandating continuing education
- The impact of this approach has not yet been fully evaluated
- Sets a precedent that may be undesirable
- May be able to use “half-steps”, such as specifically asking renewing practitioners to indicate hours of content in topic area

Changing Policies



- Address language related to Principle of Double Effect wherever it is found
 - Not necessary for enforcement of statute; its elimination would not change the standard by which practitioners would be judged
 - Does not materially help practitioners
 - Reinforces notion that opioids kill people—could have a chilling effect

Changing Policies



- Clean up language in Medical Practice Act, which says that “excessive” prescribing is grounds for disciplinary action
 - “Excessive” is very hard to define
 - Alternative is to refer to the standards set forth in the Controlled Substances Act

Changing Policies



- Open a dialogue with County and District Attorneys Association regarding process to be undertaken when deciding on charges against a practitioner
 - Would reassure practitioners that they will be judged by someone who has sufficient knowledge and experience
 - Would help prosecutors by establishing a standard process

Medicare/Medicaid Drug Coverage



- Restrictions on pain management drugs provided by Medicare and Medicaid could produce adverse outcomes for patients and the state
- Restricted access could impair pain management and result in greater costs from other parts of the programs
- Access to pain medications needs to be as complete and unrestricted as possible

“No patient should ever wish for death due to a physician’s reluctance to use adequate amounts of effective opioids.”

Jerome H. Jaffe, MD

HEALTH CARE STRATEGIES COMMITTEE OF THE KANSAS SENATE
PUBLIC TESTIMONY ON CRITICAL ISSUES IN END OF LIFE CARE – ARTIFICIAL NUTRITION AND HYDRATION AND
ADVANCE CARE PLANNING
Tuesday, February 21, 2006
State Capitol, Room N-231
John G. Carney

Senator Wagle and Committee members, thank you for the opportunity to present these remarks for your consideration. Your responsibilities in establishing sound public policy that both protects Kansans and insures that their private healthcare decisions remain private is a balancing act that requires both grace and wisdom. I do not envy you in your work, but I do caution you in embracing well intentioned efforts that may lead us down a path that none of us envisioned.

Yesterday afternoon upon finishing an hour long radio interview on the subject of artificial nutrition and hydration with a respected Kansas health care reporter who was preparing an 8 minute segment for an upcoming broadcast, he leaned back in his chair, rubbed his head, sighed and said, "I have no idea how I am going to boil this down into an eight minute spot. If I could give you all eight minutes, I still would not do this issue justice." We had talked briefly before the interview began about how "big" this issue really was. It's huge. It's complex. It's emotional. It's visceral. It's deeply personal, and unfortunately it has become overly politicized. He got it. This is a bright man. He's a father who lost a disabled teenage son. In our parting comments he claimed even after his loss – I just don't know what the answer is. I agree, and my only caution to you is to be careful in too swiftly assuming that there is any quick fix to the dilemmas we face at the end of life. Technology and the science of medicine may offer remedies and interventions but those are no substitutes for the personal decisions that patients and families face when the tentative and uncertain overwhelm. We have, in the last decade in this country, finally faced the reality that medical treatment can and often does create "mechanical paths to death" extracting a toll in some cases worse than the ravages of a mortal illness.

This is the third occasion I've had to testify on these matters to the legislature this session. Copies of my previous testimony are provided as appendices to this text. I will also be providing you a copy of the LIFE Project Public Policy Monograph published last month on this topic as well. Links to documents will be provided in electronic versions of this communication.

The remainder of my remarks will draw primarily from my previous testimony to support the following conclusions and recommendations:

- The vast majority of Kansans do not have advance directives in place, nor do they readily discuss end of life matters with family or professional caregivers, nor are most healthcare consumers familiar with the dying process, advance disease states, or chronic illness and comorbid conditions.
- Chronic disease is quickly becoming the leading cause of disability in the US. If Kansans affected by chronic disease are defined as disabled persons under the proposed provisions the number of guardianship appointments will increase markedly.
- Kansans are not at risk of professional caregivers abandoning their obligations under license. Physicians and nurses are obliged to follow standard practice guidelines. Governing bodies for the healthcare professions in Kansas offer protections for all Kansans regardless of (dis)ability.
- Before any statutory requirement is adopted that stipulates Kansans must have written advance directives in place that contemplate specific "current circumstances" at some point in the future, significant efforts need to be expended ensuring that advance directives are understood and adopted.
- The December 2005 recommendations from the Kansas Judicial Council on the obligations of guardians in the decisions to withhold and withdraw nutrition and hydration should be considered before any other measures.
- Food and water, along with air and elimination are normal functions for all human beings. Medically assisted administration, if considered ordinary for any, should be ordinary for all.
- Determining benefit and burden in withholding or withdrawing any form of medical treatment is part of the healthcare decision making equation, whether that individual is bound by natural obligation (parent of a minor) or legal appointment (court appointed guardian or durable power of attorney). As

Senate Health Care Strategies Committee
Date: February 21, 2006
Attachment 2

an example, even the Catholic healthcare directives dictate: "**There should be presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient**" (ERD, n. 58). (*Author's emphasis*)

- A **presumption for life** provision in statute must be supported by a definition of what "life" means. If the sole criterion for defining life is the physical function of bodily organs, assisted or not, then the **vitalist** position predominates. If such is the case, then the definition of brain death must be reexamined.
- The revised 2002 Guardianship Statute in Kansas provides explicit instructions regarding the obligations of guardians to know their wards. In most situations, guardians are family members who have cared for their wards for years. Those relationships and commitments should be valued and protected.
- Terms used in proposed statutory language such as **objectively futile** should have a firm basis in medical field or in medical ethics. No such basis exists at this time.

The recommendations we have are as follows:

- 1) Consider the Kansas Judicial Council recommendation regarding the administration of artificial nutrition and hydration for wards of the court (HB2307 Committee)
- 2) Concur with the request that all current end-of-life statutes be referred to the Kansas Judicial Council for further study and recommendation prior to the next session of the Kansas legislature.

In conclusion, I would like to point out that wiser men than we struggle with these issues and recognize them as confounding policy makers as well as families and professional caregivers. From the conclusion of the President's Council on Bioethics, I offer this sobering thought:

Here then is the most poignant dilemma faced by caregivers: not wishing to condemn the worth of people's lives, yet not wanting to bind them to the rack of their growing misery; not wishing to say they are better off dead, yet not wanting always to oppose their going hither. Under these circumstances, with no simple formulas for finding the best course of action, individuals and families must find their way, case by case and moment to moment, often with only unattractive options to choose from and knowing that whatever path they choose, they will feel the weight of the path not chosen.

FEDERAL AND STATE AFFAIRS COMMITTEE OF THE KANSAS HOUSE OF REPRESENTATIVES
PUBLIC TESTIMONY ON House Bills 2849 and 2884

Monday, February 13, 2006
State Capitol, Room S-313
John G. Carney

Chairman Edmonds and members of the Committee; thank you for the opportunity to present testimony regarding HB 2849 and 2884 on behalf of the Kansas LIFE Project. My name is John Carney and I am vice president for Aging and End of Life at the Center for Practical Bioethics in Kansas City and co-chair of the LIFE Project Public Task Force as well as a founding member of the organization. I also served as a member of the HB 2307 Committee assigned in 2005 by the Kansas Judicial Council to review proposed revisions to the Kansas Guardianship Statute related to hydration and nutrition for wards of the court.

My remarks today will be limited primarily to the provisions in the House Bills under consideration dealing with the administration of nutrition and hydration for wards of the court, and the attendant responsibilities of guardians in medical end of life decisions for their wards.

For most of my professional career I have worked in the realm of hospice and palliative care – at the local level in south central Kansas, at the state level, within the region and nationally, having served on the boards of directors of state and national hospice and palliative care organizations including a brief stint as the latter's chief operating officer. That professional experience notwithstanding, what I believe provides me far more meaningful perspective on this issue is the 26 years I assisted my mother in caring for my recently deceased father, who for more than a quarter of a century was disabled by stroke, facing the slow and often undetectable diminishment of his ability to care for himself. I stand before you, not so much as a career professional, but more as a son and family caregiver who knows the meaning of providing and deciding with and for a disabled person.

Secondly, in the broader context of my professional work it has been my experience that Kansas healthcare professionals are guided in their end of life care practice by the following convictions:

1. Respect for the principle of personal autonomy is pervasive, protected not only for those who can speak for themselves but equally for those who rely on others to speak for them. This conviction ensures access to safe, appropriate medical care regardless of (dis)ability. For the most part it also includes a respect to honor the wishes of patients when those desires are known regardless of whether they are expressed in writing or through a silent nod or a squeeze of the hand.
2. We respect the accrediting, credentialing and licensing processes that govern our healthcare care system to ensure competent medical practitioners. We rely in the obligations dictated by license and professional standard for those professionals to act in our best interest.
3. Healthcare decisions are first and foremost private matters between patients and their professional caregivers, naturally inclusive of those who by patient choice or legal appointment become involved.
4. Dying has changed. From this point forward, death for most of us will no longer result from a single acute event, but rather from a series of slow and often imperceptible changes – disabling over time; the result of multiple chronic diseases that ebb and flow. This process of subtle decline will be affected by new medicines and new procedures, but only rarely by new discoveries. For the majority of us the most common disability we face is dementia, the ability to make reliable decisions.
5. We cannot know, direct or predict with specific certainty today what future treatment decisions we will be asked to make for ourselves or for those we love. While we may describe our values, express our desires and discuss our intentions in healthcare directives based on today's understanding of our health status and current medical interventions, we must trust and rely on those expressions to guide our proxies and agents in the future.

6. All medical procedures, especially those requiring surgery and the administration of anesthetics just as all medications, carry risks, burdens, side effects and benefits which must be measured, weighed and evaluated by patient, family and medical professional.
7. Dying is part of life. Death will come to all of us. Though unwelcome it does not have to be inhumane, nor must it at every turn be the enemy to be avoided at all costs.
8. Within the last 10 years, Americans have discovered that modern medicine is capable of creating "mechanical paths to death" whose impact can be more devastating and burdensome than the natural progression of some mortal diseases.

How do we balance the need to protect those who are vulnerable, whose wishes may be unknown or unknowable with the private healthcare decisions of patients and families who decline or refuse treatment?

First and foremost, overwhelming evidence suggests that relying on existing written advance directive will not achieve that end. A number of recent studies including one sponsored by the Pew Charitable Trust released in early 2006, point to the woeful progress in the Advance Care Planning arena. This is not a subject Americans approach comfortably or handle well even in conversation let alone in writing. Many may speak with family members but do not, as a rule, write their wishes down or discuss them in detail with their physicians. Physicians also express reluctance in discussing the issues with patients. Consider the following facts:

- 1) Only a minority of Americans even have advance healthcare directives in place. Unfortunately in many instances they are unavailable at the time they are needed for healthcare providers and evidence points to their not being honored due to standard protocols that favor treatment.
- 2) Most advance healthcare care directives are not explicit, often describing values, treatment **preferences** and general conditions. Topics such as hydration and nutrition, while referenced may offer no instruction or guidance on, as proposed language requires, "current circumstances."

The reliance of House Bills 2849 and 2884 on previous explicit written instructions, when no such support or structure within the healthcare system exists is unrealistic and problematic.

Before proceeding with further analysis of the measures under consideration, it is important to point out that the particular provision related to the withholding and withdrawal of nutrition and hydration for wards of the court was referred to the Kansas Judicial Council during the interim session last summer and fall. The work group assigned to study the provision was named the **HB2307 Advisory Committee**. I, along with representatives from the legislative and judicial systems; healthcare ethics, legal, nursing and medical professions; long term care, hospice and disability fields met for five months to address the language. Our recommendations were forwarded to and approved by the Judicial Council in December 2005. The language recommended by Council is not part of either of these two bills.

Furthermore, the provision [59-3075 (e)(7)(C)] is still part of HB2307 in the House Judiciary Committee and Senate Bill 92. Given the uncertainty of where the Judicial Council's report will be reviewed, it seems premature to act on yet another version of the language before full consideration is given to the Judicial Council's recommendation.

As an example, new language appearing in both 2849 and 2884 references the term **objectively futile** as if it had some basis in ethical or medical literature. To our knowledge there is no accepted term in either field, and in fact AMA ethics representatives indicate that disagreement exists on the use of the term **futile** itself, some arguing that it has negative values associated with it, is ultimately subjective in nature and can effectively be applied only retrospectively. In this application, the reference to **objectively futile** may serve neither ward nor guardian.

The Center for Practical Bioethics is currently involved in an almost year long process with member Kansas City area hospitals in developing a policy guidance document on the use of the term futility. Focus group feedback from disability and minority stakeholder groups reflect **no consensus on the use**

of the term futility. Requiring this level of evidence may not prove helpful to either the affected parties or the court. At the outset the use of the term appears problematic.

In addition, how is it that the court system is better equipped to handle these delicate, gut wrenching, emotionally charged issues than are healthcare professionals, carefully selected and legally bound guardians, and family members? Thousands of these kinds of decisions get made daily in the privacy of homes, hospitals and nursing homes in the best interest of disabled patients without incident.

No evidence of the system failing Kansans was presented during the five month review conducted by the HB2307 Committee for the Judicial Council. Despite the lack of evidence, the committee nonetheless made a number of recommendations to accommodate perceived risks. Those recommended changes deserve serious consideration.

To assume that surgical procedures performed on disabled persons would not be considered medical care if the purpose is to provide artificial hydration and nutrition appears to be contradictory. Would surgeons and physicians be exempt from liability should the procedures fail? Why do the provisions not include efforts to assist with artificial or mechanical assistance for breathing or elimination – two other equally important physical requirements for sustaining life?

The assumption that these two procedures (hydration and nutrition) are fundamentally different than others, outside the parameters of medical care, and carry no **relative** risks oversimplifies the complexity of caring for disabled persons usually affected by a multi-organ and multiple system issues.

Reducing or limiting the physician's reasonable medical judgment in addressing burden and benefits of interventions or risks (side effects) to "hastening death", "medical impossibility" or incapacity again appears to oversimplify the physician's responsibility to manage the patient's care.

Finally, the most troubling dilemma raised in these proposed measures is the provision for "presumption of life", only because the definition of what it means to sustain or preserve life is never addressed. Nearly every religious and philosophical tradition, from east to west, accepts the purpose of life as being more than the physical function of bodily organs. Humans are social animals, functioning within family systems and social units. Meaning in life, for most of us comes not only from within but from outside of us as well – through a higher power or social construct. There is a give and take with the world.

If the presumption of life argument is followed to its natural conclusion, without definition as to what preserving and sustaining life means, then the bodily function of organs, mechanically assisted or artificially supported, most likely wins out. But can we stop at hydration and nutrition? If preserving and sustaining life finds its meaning in organ function, assisted or not, then we need to return to the question of what society in general has already resolved - the meaning of brain death; what it means to be an organ/tissue donor and how can anyone can determine when my time has come.

John G. Carney
Co-chair LIFE Public Policy Task Force
LIFE Project Foundation
Wichita, KS
316.263.6380

Critical Issues in End of Life Care Advance Care Planning & Artificial Nutrition and Hydration

Testimony - January 17, 2006

*John G. Carney, Vice President, Aging and End of Life
Center for Practical Bioethics and Chair of the LIFE Project Public Policy
Task Force*

What makes good EOL policy?

- Good public policy follows common sense and what Americans/Kansans value
 - Family decision making
 - Physician Involvement
 - Good Pain Control and Symptom Management
 - Autonomy and Independence (Honoring Wishes)
 - Informed Consent
- Sound Policy guides good legislation

Policy and Practice Values and Assumptions

- Professional Codes of conduct for practitioners exist to protect patients.
 - Patients make their own health care decisions when able.
 - End of life decisions are private matters between family members and their providers
 - State statues shield healthcare from civil and criminal prosecution when acting in accordance with patients wishes
 - Persons unable to speak deserve an advocate to protect their interests. A state's interest becomes active only upon an appointment of a guardian.
 - Administration of artificial nutrition and hydration (ANH) is defined as treatment based in science; considered a medical intervention
 - Guardianships appointment is a course of last resort.
- What is the current status of advance healthcare directives in Kansas?

Kansas Statutes addressing End of life

- Living Will Statute (KSA 65-28, 101)
- Power of Attorney Statute (KSA 58.625-632)
- Pre-Hospital DNR Statute (KSA 65.4941)
- Guardianship provision on withholding and withdrawal of hydration/nutrition [KSA 59-3075 (e)(7)(C)] – HB2307/SB92 (KS Judicial Council); 2006 session - HB 2848, HB2849, HB 2884

Kansas Advance Healthcare Directive – Living Will

- Strengths
 - Serves as a records of patient's wishes
 - Guides family and practitioners when patients cannot speak or loses capacity to judge
- Weaknesses
 - As a rule we don't do them/can't find them
 - Effective only upon incapacity
 - Not viewed by patient/family as process (changing over time)
 - Static - Cannot anticipate complex circumstances
 - Often onerous process defined by statute
 - Formats and legal language vary state by state

Kansas Advance Directive – Durable Power of Attorney for Healthcare (DPOAHC)

- Definition
 - a legal document used to appoint a particular person to make medical decisions for someone who is incapacitated. Appointee may be called a "surrogate," "health care proxy," "attorney-in-fact," or "healthcare agent."
- Strengths
 - Clear authority for proxy to make all decisions even unanticipated
 - Powers can be restricted
 - Provides alternative to static document
 - Guide for proxy can be included in appointment
- Weaknesses
 - Appointment often incidental with little guidance
 - Often ineffective in emergency situations
 - Practitioners often follow routine protocol without consulting proxy
 - Effective only upon incapacity

Kansas Advance Directive – Pre-hospital DNR

- "Do-Not-Resuscitate" Order: instructions prepared by a physician directing health care providers to refrain from cardiopulmonary resuscitation (CPR) if patient has no breathing or heart beat.
- Strengths
 - Specific Clearly written order by licensed provider limiting invasive attempts anticipated to be ineffective or contrary to patient wishes
 - Can avoid anguishing decisions to withdraw treatments later
 - Protects first responders when honoring stated wishes
- Weaknesses
 - Difficult to honor in emergency situations
 - Limited in scope to specific heart/lung failure
 - Often misunderstood as blanket health care directive limiting all invasive measures.
 - Often does not transfer well between settings

Addressing weaknesses Retaining strengths

- Recognize changes in aging and treatment
- Look to other states for models that work

#1 - Examine Distinctions in Decision Making

- Determining Informed Consent
- Surrogate Obligation to perform substituted judgment
- Principle of "best interest" when substituted judgment cannot be determined
- Burden of proof – clear and convincing evidence in honoring wishes

#2 – Look at Status of guardians in end of life decision making for wards

- **Comprehensive overhaul of the statute in 2002**
 - Limits and Exceptions clearly spelled out
 - Many states' silent on this issue

#3 Ensure protection for interests of disabled who cannot speak for themselves

- Determine Priority of the process
 - Personal/Family Decision
 - Medical Decision
 - Civil Rights Issue

Models in other states - Trends and Issues

- Alternatives/Advances in Advance Directives
 - Effective prior to complete incapacity
 - Digital Repositories (NC/VT Statutes)
 - Incorporate health care directive into DPOA
- Alternatives to Appointing Proxies
 - Combining statutes into one
- Alternatives to DNRs
 - POLST Forms – Physicians Orders for Life Sustaining Treatment
 - Comprehensive Treatment plan covering variety of conditions and preferences
 - Ensures physician and family involvement
 - Updated on a regular basis

The reality of finality

- We all know death will come.
- When it comes to dying, regardless of age, race, ethnicity, religious tradition we all pretty much want the same things.
- Despite that, most of us do not...
 - prepare for death,
 - talk about it with loved ones, or
 - share our desires with professional caregivers

Final thought...

*I'm not afraid to die,
I just don't want to be there when it happens.*

Woody Allen

SOUNDING BOARD

**Appropriate Use of Artificial Nutrition and Hydration —
Fundamental Principles and Recommendations**

David Casarett, M.D., Jennifer Kapo, M.D., and Arthur Caplan, Ph.D.

For two decades, clinicians have been guided by an agreement about the appropriate use of artificial nutrition and hydration (ANH). In general, ANH has been seen as a medical treatment that patients or their surrogates may accept or refuse on the basis of the same considerations that guide all other treatment decisions: the potential benefits, risks, and discomfort of the treatment and the religious and cultural beliefs of the patients or surrogates. Although this agreement has never been universal, it is well established among ethicists,¹ clinicians,^{2,5} and the courts. For instance, the 1990 Supreme Court decision in the well-known case of Nancy Cruzan specifically stated that the administration of ANH without consent is an intrusion on personal liberty.⁶⁻¹¹

However, this agreement has faced recent challenges to its legitimacy. For instance, even though the cases of Terri Schiavo¹² and Robert Wendland¹³ were complicated by disagreements among family members, the cases also involved public questioning of the premise that decisions about ANH should be made in the same way in which decisions about other treatments are made. Similarly, a recent papal statement that strongly discourages the withdrawal of ANH from patients in a permanent vegetative state will have a profound effect on decisions about ANH if it is accepted into Catholic doctrine.^{14,15} Several states have made the withdrawal of ANH more difficult than the withdrawal of other forms of life-sustaining treatment.¹⁶

Clinicians also face substantial obstacles that prevent them from applying sound, ethical reasoning when discussing ANH with patients and families. For instance, patients and families are often not fully informed of the relevant risks and potential benefits of ANH.¹⁷ In addition, financial incentives and regulatory concerns promote the use of ANH in a manner that may be inconsistent with medical evidence and with the preferences of patients and their families.^{18,19} Finally, preferences about ANH may not be honored

after a patient is moved from one care setting to another.²⁰

It is not possible to prevent all disagreements about the use of ANH. But it is possible, and indeed it is essential, to clarify the principles that should underlie decisions about ANH and to ensure that these principles guide decisions in clinical practice. Therefore, in this article we examine the ethical principles that have guided the appropriate use of ANH during the past 20 years and recommend steps to promote clinical practices that are more consistent with these principles.

CLINICAL DECISIONS
AND MEDICAL EVIDENCE

ANH is usually administered enterally through a nasogastric tube or a gastrostomy or jejunostomy tube that is placed with fluoroscopic or endoscopic guidance. ANH may also be administered parenterally through peripheral or central venous access. Hydration alone can also be provided by subcutaneous infusion.

ANH may improve survival among patients who are in a permanent vegetative state. These patients may live for 10 years or more with ANH but will die within weeks without nutritional support.²¹ Parenteral ANH can also prolong the lives of patients with extreme short-bowel syndrome,²² and tube feeding can improve the survival and quality of life of patients with bulbar amyotrophic lateral sclerosis.^{23,24} Finally, ANH may improve the survival of patients in the acute phase of a stroke or head injury^{25,26} and among patients receiving short-term critical care,²⁷ and it may improve the nutritional status of patients with advanced cancer who are undergoing intensive radiation therapy^{28,29} or who have proximal obstruction of the bowel.³⁰

There is less evidence of benefit when ANH is used for other indications. For instance, some studies suggest that ANH improves the survival rate among patients receiving chemotherapy,³¹

THE NEW ENGLAND JOURNAL OF MEDICINE

but other studies do not support this finding.^{32,33} Studies of the effect of ANH on complication rates after cancer surgery have also produced conflicting results.^{34,35} The bulk of the available evidence suggests that ANH does not improve the survival rate among patients with dementia.^{36,36-39}

ANH is associated with considerable risks. For instance, patients with advanced dementia who receive ANH through a gastrostomy tube are likely to be physically restrained and are at increased risk of aspiration pneumonia, diarrhea, gastrointestinal discomfort, and problems associated with feeding-tube removal by the patient.^{36,40-42} In addition, when a patient's renal function declines in the last days of life, ANH may cause choking due to increased oral and pulmonary secretions, dyspnea due to pulmonary edema, and abdominal discomfort due to ascites.

ETHICAL PRINCIPLES
FOR DECISION MAKING

Because ANH is associated with uncertain benefits and substantial risks, it is essential to ensure that decisions about its use are consistent with the patient's medical condition, prognosis, and goals for care. Therefore, decisions about ANH require careful consideration of its risks and potential benefits.

Decisions about the use of ANH should be made in the same way in which decisions about other medical treatment are made. Many people believe that nutrition must always be offered, just as pain management, shelter, and basic personal care must be. This view is deeply rooted in cultural and religious beliefs.⁴³ It is often expressed with the use of the word "starvation"^{44,43-45} to describe the condition of a patient who does not receive ANH. Patients, families, and physicians are entitled to hold these beliefs, which are not easily set aside. However, to help patients and families make decisions about ANH, physicians should present the contrary view by emphasizing three key points.

First, physicians should emphasize that ANH is not a basic intervention that can be administered by anyone, as food is. ANH is a medical therapy administered for a medical indication (e.g., dysphagia) with the use of devices that are placed by trained personnel using technical procedures. ANH therefore has more in common with other surgical and medical procedures that require technical expertise than with measures such as sim-

ple feeding. Second, physicians should explain that unlike the provision of food or other forms of comfort (such as warmth or shelter), the procedures required for ANH and the subsequent administration of ANH are associated with uncertain benefits and considerable risks and discomfort.^{35,35} These factors need to be considered carefully before ANH is initiated. Finally, physicians should clarify that the goal of ANH is not to increase the patient's comfort. In fact, during the administration of high-quality palliative care, symptoms of hunger and thirst generally resolve in a short time or can be managed effectively (e.g., mouth dryness can be alleviated with ice chips) without the provision of ANH.⁴⁶⁻⁴⁸ Throughout the comprehensive informed-consent process for patients and families, physicians should explain the potential benefits of ANH for a patient, as well as its risks and discomfort and all relevant alternatives, just as they would for other health care decisions.^{8,49}

After this discussion, patients and families may remain convinced that ANH differs from other treatments. Beliefs about food and the associations concerning food are deep-seated, and in some cohorts and communities they are linked to historical or personal experiences with starvation (e.g., during the Holocaust or the Great Depression). Patients and families may decide to accept or refuse ANH on the basis of these beliefs. When physicians have beliefs about ANH⁵⁰ that prevent them from supporting the decision-making process of a patient and his or her family in an unbiased way, they should consider transferring the patient's care to another physician. Hospitals and health care facilities should support physicians in doing so.

WITHHOLDING OR WITHDRAWAL
OF TREATMENT

Many people believe it is more acceptable to withhold a treatment than to withdraw it,⁵¹⁻⁵³ and one cannot discount the emotional burden that families in particular may feel when they believe that the withdrawal of treatment will allow a patient to die. This distinction is not supported, however, by currently accepted ethical and legal reasoning.^{3,49,54-57} In fact, a more cogent argument can usually be made for the withdrawal of ANH after it has been administered for a trial period if it has proved to be ineffective or if experience has provided more information about its risks and discomfort.

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EVIDENCE OF PATIENT PREFERENCE

When a patient lacks the capacity to make decisions, a single surrogate (usually defined in a state law according to a hierarchy) should make choices on that patient's behalf on the basis of available evidence of the patient's preferences and values.⁵⁸ These decisions may be based on previous statements (either oral or written) by the patient or on a surrogate's knowledge of the patient. This standard of surrogate decision making has been widely supported in the law^{57,59} and among ethicists.^{49,60} In some states, however, a patient's advance directive must include a statement that the patient would not want ANH.^{56,57} This higher standard of evidence is inappropriate for two reasons.

First, decisions about ANH should not be held to a higher standard of evidence, because the balance of risks and potential benefits is, in most situations, no different for ANH than for many other medical treatments. For many patients, such as those with dementia, the balance may favor other interventions over ANH. Therefore, it is illogical to require a higher level of evidence in order to withhold or withdraw ANH than would be required for other medical treatments or procedures that offer a similar risk-benefit balance.

Second, a higher standard that requires specific evidence of a patient's preferences regarding ANH is not realistic. Although in its decision in the Cruzan case, the Supreme Court upheld the constitutionality of requiring clear and convincing evidence of a patient's preferences,⁶ any higher standard has proved to be very difficult to satisfy. Despite moderate increases in the prevalence of advance directives as a result of the Patient Self-Determination Act, most adults have not executed a written advance directive,⁶¹⁻⁶³ and even those who have may not have specified their preferences about ANH. Therefore, a higher evidentiary standard makes it harder for surrogates to make decisions that reflect a patient's goals and preferences. Furthermore, a higher standard is illogical because it would permit certain restraints on liberty — the imposition of ANH without consent — whereas impositions of other treatments are prohibited.

LACK OF ADVANCE DIRECTIVE

Although surrogates should make decisions on the basis of a patient's preferences, sometimes an advance directive is not available. In this situation, the patient cannot be assumed to want ANH. Indeed, there are a variety of reasons why patients

do not complete advance directives, including cultural concerns, lack of information, and reluctance to initiate discussions about advance directives.⁶⁴⁻⁶⁶ When a patient's preferences are unknown, surrogates must consider how a reasonable person with a cultural background, life experience, and worldview similar to the patient's would weigh the risks and potential benefits of ANH. This "reasonable person" standard often may be easier to apply than the related "best interest" standard, which requires surrogates to consider the difficult philosophical question of whether a decision that could result in death is in a patient's best interest.

Although only a minority of states explicitly permit the reasonable-person standard,⁵⁷ reasonable people often choose to forgo life-sustaining treatment if its discomfort outweighs its benefits⁶⁷⁻⁶⁹ or if those people perceive a health condition to be worse than death.^{69,70} The balance of risks and potential benefits for ANH may be less favorable than the balance for other treatments that surrogates refuse on a patient's behalf. Therefore, states that allow surrogates to make other health care decisions on the basis of a reasonable-person standard also should permit this standard for decisions about ANH.

PROVISION OF PALLIATIVE CARE

Patients who forgo ANH may experience hunger or thirst. Although hunger typically resolves after several days, thirst may persist.⁴⁶ Other symptoms attributable to the withholding or withdrawal of ANH include dry mouth, confusion and delirium, and diminished alertness.⁴⁶ Some of these symptoms (in particular, altered mental status) are part of dying and may occur during any progressive illness.⁷¹

When ANH is withheld or withdrawn, physicians should reassure patients and families that most of the resulting discomfort can be managed effectively.⁷²⁻⁷⁴ Altered mental status can often be prevented by environmental modifications (such as reducing noise at night and placing orientation cues in patients' rooms), and delirium can be treated pharmacologically.⁷² Thirst and mouth dryness can be alleviated with ice chips, a mouth rinse, or moistened swabs.⁴⁶ Evidence suggests that these and other interventions can help ensure a comfortable death.⁴⁶ All patients who forgo ANH should be offered comprehensive palliative care, including hospice.^{3,73} A comprehensive palliative care or hospice plan should address physical and psychological symptoms and should

include emotional and spiritual support as well as bereavement support for the family after the patient's death.⁷²

OBSTACLES TO ETHICAL DECISION MAKING

Despite general agreement about these ethical principles, their application to decisions about ANH at the bedside may encounter numerous obstacles. We propose the following five recommendations to help ensure that patients and their families retain the right to make decisions about ANH and that these decisions are supported at the bedside by health care providers, by the law, and by the health care system.

First, given the inadequacies in the typical informed-consent process for ANH,¹⁷ all clinicians need to be better able to engage patients and families in meaningful discussions. Medical educators should better prepare clinicians to engage in these and other difficult end-of-life discussions by emphasizing both the ethical principles that underlie decisions about ANH and effective communication techniques. Reimbursement for physicians will also need to be increased proportionally, because effective, comprehensive discussions about ANH are time-consuming.⁷³ It will be important to ensure that physicians and other clinicians have access to thorough nutritional assessments for the patient and to effective decision aids.⁷⁴

Second, decision making about ANH in nursing homes should be shielded from financial and regulatory pressures. Although the loss of the ability to eat is an expected part of dementia, one third of cognitively impaired nursing-home residents have a feeding tube.⁷⁵ Nursing homes should not be reimbursed at a higher rate for residents who are receiving ANH than for those not receiving ANH,⁷⁶ since providing ANH costs less than feeding by hand.^{16,77} In addition, staff and surveyors should be informed that nursing homes should not be cited when a patient loses weight after a decision to forgo ANH.⁷⁸ Finally, publicly reported data on weight loss, which are available on the Centers for Medicare and Medicaid Services Web site,⁷⁹ should exclude data for residents whose weight loss is the result of a choice to forgo ANH.

Third, state laws should allow the same standard of evidence of a patient's preferences for decisions about ANH as they do for other deci-

sions. These laws should allow families to make reasoned and caring decisions on the patient's behalf if they are based on knowledge of the patient's values and preferences. If a patient's preferences are unknown, surrogates should be allowed to make decisions, in close collaboration with the patient's health care providers, that are guided by thoughtful judgments about what a reasonable person would choose. The Uniform Health-Care Decisions Act achieves most of these aims in a clear and thoughtful way and should be adopted by state legislatures.⁸⁰

Fourth, attorneys, physicians, and other health care providers should encourage and help patients to complete advance directives and to include preferences about ANH. Because decisions about ANH are often complicated by disagreements among family members, advance directives should also identify a decision maker. More generally, state laws should specify a hierarchy of decision makers to reduce the possibility of ambiguity and conflict among family members.

Fifth, health care facilities should ensure that preferences are respected in all health care settings. Problems with information transfer between institutions can affect all patients and are particularly common when nursing-home residents are transferred to a short-term care setting.⁷⁹ Nursing homes and hospitals should develop effective documentation strategies, such as Physician Orders for Life-Sustaining Treatment forms, which ensure that a patient's preferences are clearly documented and readily available to guide the patient's care.^{81,82}

CONCLUSIONS

Patients and families should be allowed to make decisions about ANH in an informed-consent process that is guided by well-established principles. Moreover, the right of the patients and their families to make independent decisions about ANH and other medical treatment should be defended against legal, financial, and administrative challenges at the bedside. A variety of stakeholders — including organizations of medical professionals, legal associations, and other health care organizations — will be needed to ensure this defense. Through advocacy activities, disease-based organizations can also help guarantee that all patients who forgo ANH receive high-quality, compassionate care near the end of life.⁸³

But efforts by individual organizations will

SOUNDING BOARD

not be enough. In order to ensure that patients' preferences are respected and that obstacles to high-quality care are removed, these organizations will need to work together closely. Moreover, they will need to form partnerships with legislators, payers, and regulatory agencies to promote the five recommendations. More generally, efforts to facilitate decisions about ANH that are compassionate, ethically sound, and clinically reasonable need to be part of a larger agenda to improve care for all patients with serious illness.

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